The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders



Hemophilia and Thrombosis Center



HIKING THE TRAILS THIS SUMMER



Sunset at Roxborough State Park in June 2021.

Summer is here and with it comes longer sunny days and the opportunity to get out and have some family fun. Hiking is one way to get some exercise, enjoy nature and the long summer days, and spend time together. It is a fun and affordable way to experience the outdoors, connect with nature, improve your mental health, and learn new things. Whether you are at home or on a vacation, you can find a local trail to explore, and hiking is easily adapted to all levels of experience and ability.

Planning a hike can be as simple as

grabbing a few things and heading to a local trailhead, or as detailed as an extensive backpacking trip. Connect with local hiking groups, form one of your own, or just bring your kids and find a new trail on an app and explore. One great way to get started hiking is to check in with <u>Backpacks + Bleeders</u> who often have new adventures to explore hiking trails.

Whatever your plans, do a little prep work! Check the weather forecast, bring water, sunscreen, food, wear good shoes, and be ready for any medical issues, including small things like blisters-so they don't become big problems. It's helpful to have a fully charged phone, bring at least basic medical supplies, and know the location of the closest emergency room. Make sure you let someone know where you are going and when you plan to return. It is also a good idea to hike with a buddy, that way you have a person to provide support if something goes wrong.



sunscreen. It's easy to get dehydrated and sun burned hiking, especially at higher altitudes.



Use technology like smart phone apps to help you plan and navigate.

Being prepared can also altitudes. mean doing a little research before you go and that can make everything easier. From where to park, fees that may be involved, where the bathrooms are, things to look out for, or views to watch for, just checking an app can make all the difference. One of the best apps for hiking is AllTrails or alltrails.com, which is available in both a free and paid version online or on your phone.

Another amazing resource is Colorado Trail Explorer at https://trails.colorado.gov/ for both computer or as an app. This free resource has detailed information about trails and parks to explore in Colorado. There are many other helpful apps that can improve your hiking adventures. Check out this list of a few interesting hiking apps and what they can do to enhance your experience: https://www.wellplannedjourney.com/best-hiking-apps/.

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Explore more than the seats and the stage at Red Rocks. Several hikes and incredible views await! Photo:
Merilee Ashton

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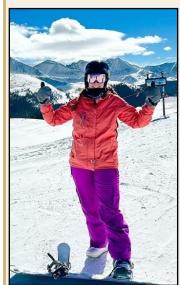
medschool.cuanschutz.edu/ hemophilia-thrombosis



Email:

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SPOTLIGHT: NIKKI CLARK, PHYSICAL THERAPIST



Nikki taking on the slopes. Photo: Nikki Clark.

Our HTC has been going through many changes in the past several years, and one positive change is the addition of several new staff members.

One such member we are happy to have working with us is Nikki Clark, who joins our physical therapy team. Nikki started about six months ago and has been a valuable asset for our PT crew! She joins Laura Singer-Fox and Joanna Roybal in bringing PT care to our patients each week.

This month we share a few things about Nikki so you

can get to know her a little better. Nikki's full, formal name is Dr. Jessica Nicole Clark, PT, DPT, TPS, but she just prefers to go by Nikki. She grew up along the East Coast of the United States and attended Pennsylvania State University in State College, PA, and then attended the University of Maryland in Baltimore, MD.

She comes from a large, close-knit family, which is spread geographically all over the United States. She spent many hours on the beach as a kid and played competitive soccer and lacrosse in high school.

Nikki joins our HTC team with a desire to help our

patients and their unique challenges as rare disease patients. She knows there is a special kind of creativity in addressing both acute and comprehensive care patients, as well as finding new ways to work with chronic pain management. She loves the teamwork and collaboration that is found at our center and finds great satisfaction in

helping our patients find the best ways to manage their health and mobility by using physical therapy.

The HTC has a unique atmosphere in that we treat patients from infancy to their advanced years.

"I enjoy the small, close-knit team, and the bond we share with our patients and their



Nikki out hiking. Photo: Nikki Clark.

community." —Nikki Clark

Nikki loves a good laugh watching stand-up comedy, the intrigue of true crime podcasts, and trying new and especially Asian-inspired foods. Her favorite places to visit are the beach or the mountains and she is happy to be here in Colorado working with our incredible patients and staff.

Next time you're in the clinic, take a few moments to say hello to Nikki! We are thrilled she's joined our team.

UPCOMING OPPORTUNITIES FOR BLEEDING DISORDER FAMILIES



Unite for Bleeding Disorders Walks

NHF Colorado: August 13, 2022 at Sloan's Lake Park, Denver, CO RMHBDA: September 10, 2022 at Billings Zoo, Billings, MT

Sign up to join NHF Colorado or RMHBDA for their Unite for Bleeding Disorders Walks! These events raise funds to make events like camp and other activities throughout the year free to families. For more info see cohemo.org or rmhbda.org.



Outreach Clinics

Our Outreach Clinics are a chance for patients outside the Denver area to meet with our clinical staff closer to their homes. Contact our front desk at 303-724-0724 for more information or to get scheduled if these locations are closer to you. See our Outreach Clinic website for details.

Sept 28-30, 2022: Missoula, Montana Oct 26-27, 2022: Billings, Montana



Pediatric Stroke Parent Support Group Resumes in September

Our support group for families of pediatric stroke survivors will not be meeting in the summer. We will resume our meetings September 12, 2022 from 6:30-7:30 pm, and will continue to meet on the second Monday of the month for the remainder of the year.

Please see our <u>website</u> or our <u>Facebook page</u> for updates. For questions or more information, contact us at <u>strokesupport@ucdenver.edu</u> or 303-724-8520.

[Continued from page 1] We have chosen a few Colorado family friendly hikes we know can be a fun getaway for families, but encourage you to explore and get out and hike this summer!

Red Rocks Park – Most people know Red Rocks as a place to go see a concert under the stars, but it is also a marvelous place to explore and hike. With resources like bathrooms, ample parking, a music hall of fame, and incredible views, it has several family friendly hikes around the property to explore. It's free to visit any day of the year from one hour before sunrise, to one hour after sunset. The amphitheater usually closes in the early afternoon if there is a concert that evening but is otherwise open for visitors to enjoy. Go to: https://www.redrocksonline.com/explore-red-rocks/recreation/

Deer Creek Canyon Park – Nestled in the foothills of Denver in Jefferson County, Deer Creek has a myriad of trails offering the feeling of being in the mountains after just a short drive from the city. Multiple trails offer a wide variety of options and plenty of views. The area is mixed use, open to hikers, horses, and mountain bikes, but be aware that there is a risk of rattlesnake encounters. It is close to Denver and can be very warm in the summer, so be sure to bring plenty of water. Go to: https://www.jeffco.us/1208/Deer-Creek-Canyon-Park.

Castlewood Canyon — Located just south and east of Castle Rock near Franktown is Castlewood Canyon State Park. The area has multiple trails with a wide variety of skill levels, including some rock-climbing areas. It offers beautiful



View from a hike at Deer Creek Canyon Park in June 2021. Photo: Merilee Ashton

terrain and interesting views not far from town. There is a fee to gain entry and the area is open from sunrise to sunset. More info at: https://cpw.state.co.us/placestogo/parks/CastlewoodCanyon/.

Roxborough State Park — Just south of town in Douglas County, is gorgeous Roxborough State Park. This park requires a car entry fee and has many amenities, such as bathrooms, curated trails, and stunning views. The location has some restrictions to preserve the natural beauty, such as no pets, drones, bikes, horses, or rock climbing, but is a destination of peace and splendor. There are multiple trails to explore and its tucked away feel is magical for visitors. Details at: https://cpw.state.co.us/placestogo/parks/Roxborough.

Staunton State Park — If you go west of the Denver metro about 40 miles on Highway 285 (Hampden) you will find one of the newest state parks in Colorado. Staunton State Park only opened in 2013 and is continually upgrading their trails and resources. The park offers acres of hiking, dramatic rock formations, beautiful views, and close access to the mountains for people of all ages and experience. The area does have an entry fee, but also has many resources and amenities, including various programs for children. Go to: https://cpw.state.co.us/placestogo/parks/Staunton/Pages/default.aspx.



Looking out from Horsetooth Mountain Open Space in March of 2017. Photo: Merilee Ashton.

Horsetooth Mountain Open Space — If you are a little further north of Denver, check out Horsetooth Mountain Open Space. The area is located just west of Fort Collins and has over 29 miles of trails to choose from. The Horsetooth Mountain trailhead is open 24 hours a day, and the area is open year-round. There is a daily permit fee for this popular location, but it includes picnic areas, restrooms, and fresh drinking water. More info at: https://www.larimer.gov/naturalresources/parks/horsetooth-mountain.

If you have questions about your health and hiking, reach out to our HTC staff. We encourage healthy exercise, such as hiking, but each individual should assess their health and abilities with their providers. Be prepared, take precautions, and enjoy all the summer has to offer making memories hiking the many trails available.

RECENT HEADLINES

These are a few of the headlines that we've recently featured on our Newsroom page or on Social Media.

Elocta (Eloctate in the US) Reduced Elbow, Knee Bleeds in Severe Hemophilia A Study

Bayer Announces Discontinuation of Kogenate FS

FDA Grants Breakthrough Status to efanesoctocog alfa (BIVV001) for Hem A

Emicizumab Safe, Effective in Hemophilia A Patients with Inhibitors

Arthritis Medicine Helps Prevent FVIII Inhibitors in Animal Study

FDA Clears Pfizer to Resume Hemophilia Gene Therapy Trial

We maintain a newsroom page at our website with a list of the news we feel may be of interest to our patients and families. Go to medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom to read more. We also share news on our Facebook and Twitter accounts.

Sign up to get this newsletter delivered directly to your email box each month! Just go to **eepurl.com/ bnszoz** and fill out the form!

UPCOMING EVENTS

Mark Your Calendars:

Please note. These dates may be <u>tentative</u> and <u>subject to change</u>. Please check appropriate websites for confirmation of events.

July 4: Clinic, Pharmacy & Admin offices closed for Independence Day

July 15-17: Teen Leadership Weekend (ages 15-17 only) with BOEC

July 17-21: Mile High Summer Camp (ages 7-14 only) at Rocky Mountain Village, Empire, CO

Aug 11-12: RMHBDA Teen Retreat — Rollins, MT

Aug 12-14: RMHBDA Family Camp — Rollins, MT

Aug 13: NHF Colorado Unite Walk — Sloan's Lake, Denver, CO

Aug 25-27: NHF Bleeding Disorders Conference, Houston, TX

Sept 5: Clinic, Pharmacy & Admin offices closed for Labor Day

See more at our Events Page on our website: medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar

Hemophilia & Thrombosis Center

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Web page:

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